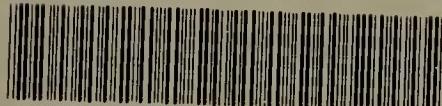


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✓**GOVERNOR'S CONFERENCE**

ON ALZHEIMER'S DISEASE



Executive Summary

GOVERNOR'S CONFERENCE COLLECTION
JULY 20 1994
Massachusetts

Compliments of the Alzheimer's Association of Eastern Massachusetts

1994 GOVERNOR'S CONFERENCE ON ALZHEIMER'S DISEASE

Executive Summary

Nearly a decade has elapsed since the Governor's Committee on Alzheimer's Disease issued its 1985 Report on the status of Alzheimer care and recommendations for action to improve services, treatment and programs for those people and families living with the effects of a dementia-related illness.

The 1985 Committee, in the strongest possible terms, stated that there was "a need for a more comprehensive and coordinated system of care" (pg. 8) with improvements required in areas including but not limited to: the provision of information to consumers, enhanced medical expertise as it relates to early diagnosis and treatment issues, services for patients and families living at home, and more accessible institutional care for those in the advanced stages of a dementing illness.

While certain aspects of those recommendations have been achieved, the "system" of care remains largely uncoordinated and fragmented with serious service gaps remaining in the continuum of care. Therefore, it is not surprising that *the key recommendation of this year's Conference is to create an Office on Alzheimer's Disease and Related Disorders at the highest level of state government.*

The mission of the Office would be to provide the leadership and vision necessary to set the agenda for quality, accessible care now and into the twenty-first century for the more than 100,000 Massachusetts residents with Alzheimer's disease and related neurological disorders. The purpose of the Office would be to coordinate, direct and oversee the implementation of state policy and services for people with cognitive impairments. In the near term, the Office would be responsible for ensuring that the recommendations outlined in the 1994 Governor's Conference on Alzheimer's Disease Report are implemented, monitored and evaluated.

At the present time, 70,000 people with dementia live in their own home or apartments, either with family or alone, and less than 5% of them receive supportive services such as day health care or home health services. Another 30,000 people reside in long-term care facilities, filling some 60% of available beds at a per capita annual average cost of \$45,000 per year.

Clearly, the human and financial cost to society is staggering. It is

estimated that the Commonwealth spends well over \$1 billion per year on nursing home care alone, not counting the cost of community-based care and acute hospital services. In the absence of any meaningful private insurance coverage for services in the home, families spend, on average, \$18,000 annually to care for a person with Alzheimer's disease. It is evident that we need to take action to meet the needs of the projected 14 million people nationwide, 350,000 in Massachusetts, who will be affected by dementia by the middle of the next century.

The 1994 Governor's Conference on Alzheimer's Disease convened to respond to this crisis. The Alzheimer's Association of Eastern Massachusetts petitioned Governor William F. Weld in December of 1992 to reconvene the 1985 Committee. In the late spring of 1993, the Governor authorized a conference to examine the broad spectrum of issues facing people with Alzheimer's disease and their families. A task force was formed, led by representatives of the Executive Office of Elder Affairs, the Department of Public Health and the Alzheimer's Association, to plan and implement the Conference.

The planning committee developed a format for the Conference, to be held on two days, May 20 and June 1. The first day was by invitation only to experts in various disciplines including state service providers and professionals in the field of dementia and elder care to serve on one of ten work groups. The second day was open to the general public where recommendations from the work groups were to be presented to people with Alzheimer's disease, their families, professionals, legislators and the Governor.

The Conference had four main goals:

- To explore gaps in services for people with dementia and their families.
- To establish recommendations for action to present to Governor William F. Weld.
- To establish a working relationship and facilitate education about Alzheimer's disease with a variety of state and community service providers.
- To establish a task force on Alzheimer's disease.

The work groups encompassed a wide range of issues and needs of people with cognitive impairments as defined by the planning committee including: dual diagnosis (mental retardation and Alzheimer's), housing, long-term care,

psychiatric/psychopharmacology, cultural diversity, acute care, patient/family/community support, legal, education, and coordination of health care in community settings.

During the months leading up to the Conference, work group participants received briefing papers and other background information, including the 1985 Report to facilitate discussion on the day of the Conference. Some of the work group co-chairs convened pre-conference planning sessions to organize their agendas and receive additional input.

On May 20, 1994, over 120 invited experts, 10-12 members per work group, met at the Deaconess Hospital in Boston and spent the day evaluating progress made since the 1985 Report was issued, perceived needs at the present time, and future issues requiring attention. The work group members were advised in advance that they needed to reach consensus with concrete recommendations for action to be presented to the Governor. To frame the day's discussions, Michael Splaine, associate director, Public Policy Division of the National Alzheimer's Association, addressed the group with a summary of the 1985 Report, a snapshot of the national picture on Alzheimer's disease as relating to health care reform, and urged the group to develop a vision for future care.

At the end of the day, each work group had indeed reached consensus with a total of forty-nine recommendations accompanied by specific action steps, designed to be accomplished in the next one to three years to significantly improve the quality of life for people with Alzheimer's disease and their families.

On June 1, at the State House's Gardner Auditorium, the public gathered to hear those recommendations presented. Lewis Weinstein, JD, chairman of the 1985 Committee, called the Conference to order and then introduced Dennis J. Selkoe, M.D.. Dr. Selkoe summarized accomplishments achieved in the last ten years and highlighted issues yet to be resolved. A draft summary report was distributed to participants as the work group chairs presented their recommendations to representatives of the Governor's office, legislators, professionals, people with dementia and their families.

Robert Blancato, executive director of the 1995 White House Conference on Aging, also spoke, noting that this was the first White House Conference on Aging event focusing on Alzheimer issues. The highlight of the morning's program were poignant remarks from two people with Alzheimer's disease, Stan Evans and Peter Murtha, and from Clara Wood, a caregiver. With family and friends in attendance, these individuals made it clear to all who listened just how devastating this disease

is and why we must act now to implement the recommendations presented.

In closing the Conference, Donald Freedman, JD, chairman of the Alzheimer's Association of Eastern Massachusetts Board, summarized common themes and issues yet to be resolved. As outlined above, Mr. Freedman stated that the overriding recommendation of this year's Conference is to create an Office on Alzheimer's Disease and Related Disorders at the highest level of state government.

Flowing from this recommendation, other key recommendations are summarized below. In the body of the Report, each of the forty-nine recommendations for action are outlined in detail with accompanying actions steps for implementation. We urge you to take the time to review each of the ten work group reports. The summary recommendations are intended to provide an overview of critical areas/issues identified by multiple work groups. Many important issues demanding action specific to a particular topic area are not captured in the summary recommendations.

Recommendations for Action

1. Expand and modify requirements for all programs so that cognitive impairments are of equal importance as physical impairments in determining eligibility criteria for services. There should be a review of the Americans With Disabilities Act to determine if there are applicable standards/mandates.
2. Design appropriate and flexible financing of services for people with dementia related illnesses wherein funding is based on the person's needs. Review and adjust, where necessary, cost reimbursement formulas to more adequately reflect the intensified care requirement of people with dementia. There should be a comprehensive analysis of Medicare, Medicaid, state supported elder home care and other subsidy/service programs to determine if they are not only cost effective but also provide consumer choice.
3. Create research protocols for dementia care including an epidemiological study to determine the incidence of people with Alzheimer's disease and those with a dual diagnosis of mental retardation and dementia. Develop program evaluation components for special care units in nursing homes, specialized adult day

programs, in-home services etc. Adopt standards or guidelines for care, such as those developed by the Alzheimer's Association, for resident care in community and long-term care settings.

4. Review nursing home regulations, guidelines and other code requirements to determine their appropriateness as they pertain to the needs of long-term care facility residents with Alzheimer's disease.
5. Create and support multicultural accountability through written standards and criteria for programs and services along with the development of multicultural networks and community partnerships to bring diversity issues to the forefront of funding, education, service development and legislative initiatives.
6. Promote universal design, home adaptation, and assistive devices to support the independence of people with Alzheimer's and to reduce the demands on caregivers. Develop alternative living arrangements such as assisted living programs which embrace the best practices of dementia care and services. Increase funding for the state's respite program by 200%; increase funding for transportation and other access services; and enact House Bill 4747/4748 which sets minimum standards for the development of assisted living programs in Massachusetts.
7. Improve coordination and increase resources for existing protective service and legal protection programs for abused elders, elders at-risk and others. Expand the pool of potential guardians. Develop policies that address the needs relative to the progressive loss of capacity of people with dementia to make informed decisions.
8. Develop and mandate dementia specific state-wide awareness and education programs directed to professionals and paraprofessionals serving people with dementia and their families, family caregivers and the public with a special emphasis on reaching underserved populations. Use the state boards of licensure as vehicles for implementation along with curricula development in various training programs.

We hope that this Report will provide the blueprint and impetus for action. Many distinguished individuals and organizations have devoted countless hours to making this Report as comprehensive as possible. Gratitude and appreciation is extended to all who have participated in this effort to date. With implementation of the recommendations will come the satisfaction of having made a real difference in the lives of Stan Evans, Peter Murtha, Clara Wood and their families, and the more than 100,000 residents of Massachusetts with dementia. Let's make sure that Massachusetts remains a leader in the compassionate care of people with Alzheimer's as it truly is the disease of this century and next!

